

Jane Smith: A Woman with a Vision

Jane Smith, founder of the Arkansas Spinal Cord Commission (ASCC), died on Sunday, July 31, 2005, in Wynne, AR at the age of 81. She was born in Wynne and lived her entire life in Cross County, AR, though her work and vision impacted people with spinal cord disabilities across Arkansas and the United States.

"Few people know the impact that this little lady from Cross County had on the lives of so many," said ASCC Executive Director Cheryl Vines. "Mrs. Smith was a true dynamo, never taking 'no' for an answer. She hired me and she often reminded me how important it was to keep our clients in the forefront."



Mrs. Jane Smith was the founder of the Arkansas Spinal Cord Commission.

Mrs. Smith's interest in spinal cord injury began in 1954, when her mother was injured in a motor

vehicle crash, resulting in quadriplegia. After initial treatment in a Memphis hospital, there was no place in Arkansas for Mrs. Smith's mother to receive rehabilitative care. Memphis doctors suggested she should take her mother home to die. After investigating other options, Mrs. Smith decided to take her mother to the New York Rehabilitation Institute, where she could work with Dr. Howard Rusk.

After Mrs. Smith's mother was released from the Institute, Mrs.

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New ASCC Case Manager in Russellville

Toney LeQuieu joined the Arkansas Spinal Cord Commission (ASCC) Case Management staff on September 12th and will be working in the Russellville office. Toney replaced Robert Griffin who retired in June after 17 years with ASCC.

Toney received his degree in Therapeutic Recreation from Henderson State University and is a Certified Therapeutic Recreation Specialist. For the last nine years he has worked at HealthSouth Rehab Hospital in Jonesboro as a Recre-

ation Therapist. His extensive experience in completing wheelchair evaluations, home evaluations and conducting patient education groups and community reentry programs will be an asset as he begins his duties as Case Manager.

In addition to his experience working with spinal cord injuries at HealthSouth Rehab Hospital, Toney has been involved with the Arkansas Disabled Sportsman Association as a volunteer event coordina-

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SPINAL COURIER

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With Thanks

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SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

2005-06 ADSA Hunts

Dear Editor:

If you [*Spinal Courier* readers] are interested in coming to any of the Arkansas Disabled Sportsman Association (ADSA) hunts for

2005-06, please contact Toney LeQuieu at **479-890-5751**.

*Jimmy Ashley, ADSA
Jonesboro, AR*

From the Director

Beginning in January, Medicare recipients will embark on a new adventure—the Prescription Drug Program. Long awaited and much maligned, the new program is not what we wanted, but it will be more than Medicare recipients, those who worked to receive Social Security benefits (not to be confused with State Supplemental Income and Medicaid), have now. As Senator Blanche Lincoln has often said, “We had to start somewhere.”

Figuring out how it will affect you and what you need to do is a challenge in itself! I have searched and researched over the past few months, trying to learn all I can about the new Medicare Part D (as the drug part of the Medicare program will be known). I had planned to write an article for this newsletter, but each time I started to write some new information came my way. I certainly do not want to misinform you.

All Medicare recipients will receive information on Medicare Part D in October. It will be your responsibility to make your decisions by January. Take time to read what you can. If you have the opportunity, go to a workshop to learn more and ask questions. ASCC miniconferences will include sessions on Part D. As we are able to find useful information, we will try to get it to you. Don't wait—check it out for yourself!

Enjoy the colors and smells of fall—my favorite season!

Cheryl L. Vines

ASCC accepts tax-deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207

Camp Aldersgate Was THE Place To Be This Summer

This summer, Camp Aldersgate was the place to be. Forty-one campers with spinal cord disabilities attended Spina Bifida Camp June 26 to July 1.

The campers were divided into two tribes: the Caddo and the Quapaw. As always, there was fierce competition between the two tribes. All week long these two teams competed in various activities to earn points. These activities included



Super Camper winner Jeremiah Brandow caught a good sized catfish during the fishing tournament.

nature hikes, outdoor cooking, arts and crafts, swimming, fishing, drama and music, accessible adventure/challenge ropes course, hand and/or foot driven catamarans, adapted archery, horse-back riding and, for older campers, scuba diving.

On Friday morning family members and Camp staff filled the Commons Building for the awards ceremony. Excitement grew as the campers piled into the auditorium.

Jeremiah Brandow of Flippin, AR was awarded the Joe Morgan Super Camper award.

This year the Wheelin' Sportsmen AR Chapter sponsored a fishing tournament. The third place award went to Trice Marshall of Warren, second place went to Ashlynn Redman of Jacksonville, and the first place award went to Danielle Freeman of Pocahontas, with a fish weighing 5 lb. 14 oz.

At last the final tally was done, and the winning tribe was announced. This year's winner was the Caddo tribe!

Spina Bifida Camp is a collaborative program supported by the Arkansas Spinal Cord Commission, Camp Aldersgate and Med-Camps of Arkansas.

If you missed Camp this year, and want to participate next year, be sure to look for details in our January 2006 newsletter, talk with your Case Manager or contact Mary Jo Stanton at **501-296-1788** or **800-459-1517**, or by e-mail at mjstanton@arspinalcord.org

News from Spina Bifida Association of Arkansas

The Spina Bifida Association of Arkansas (SBAAR) presented five \$500 scholarships to Arkansans with spina bifida who are pursuing higher education. They are:

Justin Bickell, University of Central Arkansas

Charity Chambers, University of Arkansas, Fort Smith

Aaron Combs, Harding University

Tyler Garner, University of Texas, Arlington

James Rucker, Louisiana State University

This year SBAAR was the recipient of a \$5,600 gift from the Corvette Club of Arkansas to help the Spina Bifida Association sponsor their scholarships and other programs.

Mark your calendar!

◆ SBAAR's Second Annual Family Fun Fest, **October 15, 2005**, will be held at Camp Aldersgate in Little Rock. The day will be filled with educational sessions,

resource sharing, Halloween crafts and games, good food and great fellowship. Contact Vicki Rucker, **501-978-SBAA (7222)** to reserve your spot.

◆ SBAAR's Annual Christmas Party is scheduled for Sunday, **December 4th** at Camp Aldersgate. Activities will include seasonal music, singing, games, refreshments, gifts and a visit from "you know who." Contact Vicki Rucker, **501-978-SBAA** to reserve your spot.

Spina Bifida: The Challenges of Transitioning into Adulthood

By Marilyn S. Pacheco, M.D.

Assistant Professor, Department of Physical Medicine and Rehabilitation
University of Arkansas for Medical Sciences

In the past, almost all children born with spina bifida (SB) died in infancy or early childhood from infection or the complications of hydrocephalus. But the advent of antibiotics and advanced surgical techniques have made it possible to achieve longer lives and increased independence. Spina bifida occurs in 7 out of every 10,000 live births in the United States. There are over 250,000 in the U.S. spina bifida community.

Let us learn the spina bifida Latin lingo. Synonyms that are used more or less interchangeably include **spina bifida**, spina bifida **aperta**, spina bifida **cystica**, spina bifida **occulta**, **meningocele**, and **myelomeningocele**.

- spina = spine
- bifida = in two parts
- aperta = open, as in “open spine”
- cystica = the cyst, or sac on a newborn’s back
- occulta = hidden form of spina bifida
- myelo = spinal cord
- meningo = meninges, the protective membranes covering the spinal cord and brain
- cele = the cyst, or sac on a newborn’s back
- neural tube = the embryonic structure that will later develop into the spinal cord, brain, and nervous system

What Are the Complications Associated with Spina Bifida?

- Full or Partial Paralysis – this depends on the level of SB
- Bladder and Bowel Control Difficulties
- Learning Disabilities – problems with motor skills, attention, memory and organization

- Depression can be seen as changes in appetite, sleep patterns, classroom concentration and daily functioning
- Latex Allergy – this develops because of the early, intense and constant exposure to rubber products through numerous surgeries, diagnostic examinations, and bladder and bowel programs
- Social and Sexual Issues – including precocious puberty

Growing into Adulthood

Thanks to new medical treatments and technology, most people born with SB can expect to live a normal life. People with spina bifida have many special challenges because of their congenital disability, but their condition does not define who they are. They have careers, get married and have children just like people who don’t have spina bifida.

People with spina bifida have many special challenges because of their congenital disability, but their condition does not define who they are. They have careers, get married and have children just like people who don't have spina bifida.

Growing into adulthood for a young person with a disability is a long-range process that usually does not happen by itself. “This transition needs time, must be purposeful and have a goal,” says Helen Healy, a director for community outreach in Bloorview MacMillan Children’s Centre in Toronto, Canada. Her key words are: **Start early, Be real and positive, Have shared expectations** and **Hope for the future**. The areas for life skills that need to be dealt with

in this transition process are five and aim at giving a person tools for problem solving and life management. They are about self, family, community, job (school) and leisure.

There are developmental tasks of adolescents with SB, including:

- Growth as a self reliant, independent individual
- Evolve toward an acceptable realistic body image
- Understanding appropriate controls of sexual drives and the individual emotional and physical capabilities for expressing them
- Participation in community activities and leisure opportunities
- Development of a plan for economic and social stability
- Demonstration of a value system to drive future decision making

Problems into adulthood include pressure wounds, obesity, incontinence, scoliosis, UTIs urinary tract

infections), shunt issues, arthritis, poor self image, sleep apnea (this is possibly due to Chiari brain stem compression or obstructive lung disease), lung health – restrictive or obstructive, sexuality, pregnancy, osteoporosis, renal issues, bowel program issues, tethering, pain and substance abuse.

Adults with spina bifida should have health checks for all body systems: blood pressure, height, Continued on page 5 - see “Spina Bifida”



Time to Get Your Flu Shot!

Influenza is a highly infectious viral disease that

occurs in the winter months (October to March). "Flu season" usually begins in November, peaks in December and is usually over by March, but it can occur as early as October.

It takes two weeks to build up immunity to the influenza virus, so it would be good to get your vaccination in October. The very young, those over 65 years of age, and those with medical conditions that place them at the greatest risk of complications should get vaccinated.

Dr. Thomas Kiser, ASCC Medical Director, recommends anyone with a spinal cord injury in the cervical region or high thoracic region (T6

and above) get a flu shot. "Because of your weak cough and decrease in pulmonary reserves you need to have the maximum protection against the influenza virus," he said.

"I also recommend a pneumococcal vaccination to anyone with a spinal cord injury," he added. "You can get it the same time as your influenza vaccination. The pneumococcal vaccination has a long term effect and is usually only recommended once in a person's lifetime. However, there is some debate about its longevity and some physicians recommend revaccination with the pneumococcal vaccine when you turn 65 years old."

Call your doctor now to set up an appointment for your influenza and/or pneumococcal vaccination and stay healthy this winter!

NEAR Support Group Discontinued

Effective November 1, 2005, the Northeast Arkansas Spinal Cord Disability Peer Support Group discussed in the April edition of the *Spinal Courier* will no longer meet. This group was scheduled to meet on the third Thursday monthly at 2:00 p.m. at the HealthSouth Rehab Hospital in Jonesboro.

"Lack of expressed interest and participation are the reasons for the decision to stop the group," said ASCC Case Manager Russell Henry. "I will be there on both **September 15** and **October 20** in case someone does attend on those dates. You can contact me at **870-268-0425**."

ICE – Must Have Cell Phone Number

Open your cell phone now and look at the list of people in your phone book. You probably have 15 or even 50 or more names listed. Now, choose the one you would want to be notified in case you are involved in an accident or emergency. Then **add the letters "ICE" before that person's name**.



ICE stands for "In Case of Emergency" and is a designation that emergency personnel understand. Ambulance Service Paramedic Bob Brothie of Great Britain, who thought up the idea of ICE, said, "Almost everyone carries a mobile phone now, and with ICE I'd know immediately who to contact and what number to ring."

Why not **put ICE in your cell phone now**? It is simple and takes only a few seconds. It could save your life, or put a loved one's mind at rest.

Spina Bifida

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weight, cholesterol levels, colon health, tetanus shots, pap smears, breast exams, testicular and prostate exam, urinalysis, renal ultrasound, renal blood test, spine x-ray, eye exams and more.

What Does the Future Hold?

Our challenge as caretakers is to anticipate the changing needs of the person with spina bifida and act as an informed resource for identified support needs. There are developing centers for adults with spina bifida in the U.S. A multidisciplinary team approach utilizing the expertise of urologists, orthopedists, neurosurgeons, physiatrists, physical therapists, occupational therapists, social workers, rehabilitation commissioner, vocational rehabilitation, orthotics and prosthetics, family and patient is essential throughout these patients' lives if they are

going to fully participate in society. The centers were established based on a philosophy of care that includes comprehensive assessment and consumer education.

Because of the complex challenges faced by adults with spina bifida, each patient receives a lifelong care plan tailored to his or her individual needs. Preservation and enhancement of function is the overall goal. It is the hope that the future is equally as bright, and that the majority of people with spina bifida can participate in society in a meaningful way.

Marilyn S. Pacheco, M.D. is a Physiatrist and UAMS Assistant Professor. She received her certifications by the American Board of Physical Medicine and Rehabilitation and Spinal Cord Injury Medicine in 2004. Dr. Pacheco accepts outpatients, including adults with spina bifida.

Up Close and Personal: Janet White

This is the eighth in a series of articles profiling the ASCC Case Managers.



Janet White began her career with the Arkansas Spinal Cord Commission in 1987 as clerical support for the Magnolia Office. While working full time for ASCC she obtained her degree from Southern Arkansas University in 1997. In 2002, the Commission had the opportunity to promote Janet and she began her Case Management duties serving ten counties in Southwest Arkansas.

According to Client Services Administrator Patti Rogers, "Janet has adapted well to her Case Manager's role. She is very dedicated and works hard to provide timely services to those individuals on her caseload." Reflecting on her role as Case Manager Janet states, "Being a Case Manager has its rewards and each individual adds something to your life. Providing assistance and helping people is the best part of my job."

Janet's dedication and willingness to help others is evident in her personal life as well. She is very active in church, working with the youth group coordinating and chaperoning trips. Those who know her well can attest to the fact that she also provides a positive role model to these adolescents.

In her spare time, Janet has become addicted to cruises. Over the past few years she has cruised to the Bahamas, Jamaica, St. Thomas and Cozumel. Be sure to keep sailing back home, Janet!

PROFILE:

Date And Place Of Birth: March 15, 1966, in Springhill, LA

Family Members: Living with me, my dog Sundance; otherwise, I have two brothers, a half sister, three nieces, two nephews and a godson

I Absolutely Will Not Eat: Sushi

One Thing People Would Find Surprising About Me Is: I like to talk

I Have A Need To Be: Organized

If I Did Not Live In Magnolia, I Would Want To Be: In Florida

My Favorite Movie Is: Ocean's Eleven

My Favorite Song Is: Dance with My Father

The Guest At My Fantasy Dinner Party Would Be: Luther Vandross—for his song, and Mickey Mouse—to remember my youth

I Am Most Comfortable With People Who Have: Patience and understanding

My Favorite Pastime Is: Reading

My Favorite Author Is: Stuart Woods

My Pet Peeve Is: People who won't take responsibility for their actions

The Best Advice I Ever Received Was: "God will not put more on you than you can handle."

My Favorite Saying Is: "Trouble doesn't last always."

I Knew I Was Grown Up When: I paid the last payment on my first car

The One Thing I Always Wanted To Do But Have Never Had The Chance Was: Teach elementary school

My Hobbies Include: Water aerobics and spending time with my many children, none of whom I gave birth to

One Word To Sum Me Up: Dependable

Jane Smith: A Woman with a Vision

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Smith returned to Arkansas and worked tirelessly to call attention to the plight of those with spinal cord injuries in Arkansas. In 1974, with the aid of then Arkansas First Lady Betty Bumpers, Mrs. Smith set up the Spinal Cord Injury Task Force of the Arkansas League of Nursing.

By going door-to-door throughout the counties of Arkansas, the nurses determined the number of Arkansans living with spinal cord disabilities. As they expected, the results of their census showed that there were many Arkansans living with spinal cord disabilities, enough to warrant state action.

In 1975, after lobbying by Mrs. Smith, Dr. Rusk and others, the Arkansas Legislature enacted Act 311 which established the Arkansas Spinal Cord Commission to provide a coordinated approach to early identification, emergency care, acute and rehabilitative treatment, and long term follow up.

An innovative concept, ASCC was the first state agency of its kind in the nation, dedicated to the unique and complex needs of citizens with spinal cord disabilities.

Mrs. Smith served as the Chairman of the Commission from 1975 until 1981, and later as a member of the Commission from 1988 to 1991. Her vision, leadership, commitment and disdain for the status quo has guided the Commission Members and staff over the past 30 years.

Mrs. Smith will long be remembered as our founder, our god-mother and our conscience.

Get Out of the House – Readers' Poll

We all have opinions and most of us do not hesitate to share our opinions. It can be said that opinions drip off of people like water from an ice cube placed in the sun on a summer day in Arkansas. Sharing is fun!

We want YOUR opinions about places that encourage you to GET OUT OF THE HOUSE. Send us your reply by regular mail or by e-mail. Those ASCC clients who reply will have their names placed in a drawing for a \$30 gift certificate from Wal-Mart.

Be sure to identify who you are and whether or not you have a spinal cord disability when you send in your response to the following poll. Please mail your responses to:

Arkansas Spinal Cord Commission: Readers Poll
1501 North University,
Suite 470
Little Rock, AR 72207

Send your e-mail responses with the subject line of **Readers Poll** to: courier@arspinalcord.org

“Get Out of the House” opinion categories are:

1. **Favorite Accessible Restaurant (Name and Location)**
2. **Best Movie Theatre (Name and Location)**
3. **Favorite Park (Name and Location)**
4. **Best Accessible Hotel/Motel (Name and Location)**
5. **Favorite Place to Shop (Name and Location)**
6. **Best Accessible Airline**
7. **Favorite Outdoor Activity**
8. **Favorite Place Away From Home (Name and Location)**

Toney LeQuieu

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tor, scheduling hunting and outdoor activities.

Toney, his wife Elizabeth and their daughter Ashley, age 7, have recently moved to Pottsville. Elizabeth began her new position in August as an Occupational Therapy instructor at UCA in Conway.

The ASCC staff looks forward to working with Toney. Please join the Spinal Cord Commission and Staff in welcoming Toney and his family!



ASCC welcomes new Russellville Case Manager Toney LeQuieu.



The Squeaky Wheel

The squeaky wheel . . . gets the grease! This column is all about grease—things that make life for persons with a spinal cord disability go smoother and ease your way in the world. “Things” can be hints, equipment adaptations, innovations, tricks-of-the-trade, procedural shortcuts, life experiences or things you “should have done but didn’t.”

Don is “stuck” on a new idea and hopes his little discovery can help others.

We’ve all had those days when regardless of how careful we are, you hear that dreaded sound: the “Roho flow” and down you go . . . flat!

I recently discovered my transfer board had sliced an L-shaped cut in my Roho cushion. It was a bad cut and I thought that was the end. My options were: try to patch it myself or pack it up and send my cushion along with \$35 to Roho and hope they can fix it. If they can’t, I’d lose my cushion and the \$35. I opted to repair my cushion with

a bottle of “Super Glue.” You can get two .11 oz. bottles, with the red top, at Wal-Mart or the Dollar Store for less than \$2.

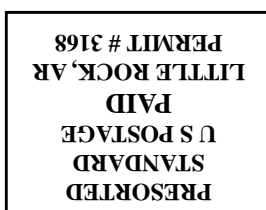
I squeezed the cut together with my fingers and squirted the glue on the cushion’s cut edges, and then released it so the edges went back together. Next, I applied a liberal bead of glue on the outside of the cut. I let it set overnight to give it time to completely dry. Next day, I aired up the cushion and was back in business! It’s

been over two months and not a leak.

Make sure you get the **Super Glue in the bottles**—the top never glues to the bottle like the tube kind and there’s no waste. Also the bottle glue seems to bond stronger than the tube. Be sure to not get the glue on yourself and keep solvent on hand for emergencies.

I keep one bottle of glue at home and one in my van. Repairs are quick, easy and cheap!

Our thanks to Don for this handy tip. **We invite you to send in your helpful hint—your bit of “grease.”** Contact your ASCC Case Manager, write us or e-mail us at courier@arspinalcord.org



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<input type="checkbox"/> Change name or address as shown on address label
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